

PANDAS and PANS Affects the Entire Family System

There is something uniquely shocking about a sudden and profound psychiatric change in a child.

A family formerly based on a productive system of consistency and sharing needs to cope with a whole new set of rules as efforts are made to heal the child. PANDAS/PANS is often a temporary illness. There will be a time when your child will heal and the current pain will be a distant memory.

Take care of yourself

Feelings of isolation, grief, and PTSD are reported by the majority of parents. Find a trusted counselor, clergy or friend to talk to. Talking to someone who has your best interest in mind will offer a release from mounting anxiety and help you remember your child will heal. Caretakers often forget to care for themselves. See your own doctor to be sure your own health needs are met. This autoimmune disease can deplete parents' energy. Allow yourself to take a breather now and then.

Siblings need support too

PANDAS and PANS is hard on siblings too. Try to spend time alone with your other child(ren). Even one hour per week alone will remind your other child(ren) that they are still loved and important during this difficult time.

PANDAS Network.org is a 501c3 non-profit corporation founded by parents of children afflicted with PANDAS/PANS. We understand, first hand, the unique challenges and fears you are facing. Uniting as a community encourages researchers to investigate and cure this autoimmune disease.

WE INFORM

- Web access to health care providers
- Online newsletters
- Research and patient education

WE CONNECT

- List of support groups
- Snapshot surveys of the community
- Professional networking

WE ADVOCATE

affiliations and partnerships with

- National Institute of Mental Health
- AARDA- National Coalition of Autoimmune Patient Groups
- International OCD Foundation

We are here for you.

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What does a PANDAS or PANS diagnosis mean to your child?

**A Resource for Families
PANDAS Network.org**

**Pediatric
Autoimmune
Neuropsychiatric
Disorders
Associated with
Streptococcal Infections**

**Pediatric
Acute-onset
Neuropsychiatric
Syndrome**



PANDAS NETWORK
ADVOCACY, SUPPORT & RESEARCH FOR PANDAS, PANS, AE

To learn more or support our work,
visit www.pandasnetwork.org

What is PANDAS and PANS?

A diagnosis of PANDAS or PANS means a child has had a sudden, dramatic change in personality displayed as Obsessive Compulsive Disorder (OCD) together with accompanying symptoms following a strep, bacterial or viral infection. Particularly in a very young child, OCD can display as intense fears or anxiety.

Symptoms may show a fluctuation pattern as the child heals. Symptoms often return or worsen when the child gets another infection or is exposed to new illnesses, even if they themselves do not have obvious symptoms like a sore throat or fever. Infections need to be eradicated. Over time, episodes can be more intense.

Researchers have begun to substantiate that this disease involves a misdirected autoimmune process that affects or weakens the blood brain barrier.

This is an inflammatory process that irritates a region of the brain called the basal ganglia. The basal ganglia are a group of structures that are an important "switching station" in the deepest inner region of the brain. This area manages a variety of functions such as movement, cognitive perception, habit, executive "logic-based" thinking, emotions, and the endocrine system.

The majority of the research has involved the strep throat bacteria, but efforts are being made to identify other known infectious agents. Subsequent episodes can be caused by other environmental and infectious triggers different than the original infection.

PANDAS and PANS Defined

PANS is defined by the following criteria:

Abrupt, dramatic onset of OCD or severely restricted food intake; symptoms are not better explained by a known neurologist or medical disorder; and the addition of at least 2 of the "accompanying" symptoms:

- Anxiety
- Emotional lability and/or depression
- Irritability, aggression and/or severely oppositional behaviors
- Behavioral (developmental) regression
- Deterioration in school performance
- Sensory or motor abnormalities
- Somatic signs including sleep disturbances, enuresis or urinary frequency

The onset of PANS may start with infectious agents other than strep. It also includes onset from environmental triggers or immune dysfunction.

PANDAS is defined by the following criteria:

Clinical diagnosis of PANDAS includes 5 criteria:

- Presence of significant obsessions, compulsions and/or tics
- Abrupt onset of symptoms or a relapsing-remitting course of symptom severity
- Prepubescent onset
- Association with streptococcal infection
- Association with other neuropsychiatric symptoms (includes any of the PANS "accompanying" symptoms)

Testing and Treatment

PANDAS and PANS are clinical diagnoses. Your provider may find the following tests helpful:

- Strep throat swab and 48 hour culture
- Blood work to test for strep (strep ASO, Anti-DNase B, and Streptozymes)
- Tests to check for other infections
- The Cunningham Panel

The Cunningham Panel is a test used in the assessment of difficult PANDAS/PANS cases. "The collective results of the panel of 5 tests will provide an assessment as to the anti-neuronal and autoimmune state of the patient at the time of testing." Learn more about this test at www.moleculera.com

Treatment varies by the needs of each child. Your provider may prescribe or suggest the following:

- Antibiotics or anti-virals
- Steroids
- Intravenous Immunoglobulin (IVIG) or Plasmapheresis (PEX)
- Therapy such as CBT (Cognitive Behavioral Therapy) or ERP (Exposure Response Prevention)
- NSAIDs (Non-Steroidal Anti-inflammatory Drugs)
- SSRI's (Experts are split on the usefulness of these drugs. The motto is "start low and go slow")